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ABSTRACT

For certain groups of the mentally ill, most notably individuals with serious mental disabilities, the community-based mental health system can be more of a "non-system." Unforeseen problems have plagued both the dream of deinstitutionalization and the effectiveness of community mental health centers during the last 20 years. Uncoordinated planning efforts between federal, state and local governments have contributed to the problem. Key coordination problems include uncoordinated care between the hospital and the community, treatment gaps and the need for a continuum of care, funding patterns which complicate coordination issues, and decreasing funds for services. Although states cannot remedy all the problems brought about by deinstitutionalization, they can ensure a future of coordinated care by enacting specific legislation and by incorporating elements basic to many successfully integrated community mental health programs. Federal money to the states for mental health and social services will probably continue to decrease. Unless states take definitive action to transfer funds and authority to the local governments already responsible for caring for the vast majority of the seriously mentally ill, states will be forced to spend more on their general mental health budgets supporting state hospitals. State legislatures can help build a better future for the mentally ill by learning the lessons of successful community based programs already exisitng within their own borders, as well as those from other states. (Specific program and legislative responses of the states are described.) (ABL)

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by

Andrea Paterson

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MENTAL HEALTH SERVICES COORDINATION: WORKING TOWARDS UTOPIA

INTRODUCTION

Today, 75 percent of services to the more than two million who suffer from chronic mental illness are provided in the community (1, p. 14). The three out of four individuals who were treated as inpatients in 1955 are now treated as outpatients (1, p. 3400). States and localities continue to build on the knowledge that many individuals with mental illness who once would have known isolation in a state hospital can and do live more productive lives in the community.

Yet for certain groups, most notably the individuals with serious mental disabilities, the community-based mental health system can be more of a "non-system." Its multiplicity of governmental units and mental health care providers can and often do operate independently of and in competition with each other.

For the individual with mental illness who has been able to forge a tenuous life for himself in the community, this lack of system coordination can have direct consequences. He may visit a psychiatrist for medication management, be involved in a day treatment program directed by a social worker, and live in a halfway house supervised by a residential director. The psychiatrist, the social worker and the residential director may all provide services to meet discrete needs, but none may be ultimately responsible for the patient's welfare. He may or may not have a case manager to help him negotiate these separate service components (2, p. 10).

He could end up in the state hospital if he finds himself without appropriate crisis assistance in time of trouble. If he remains in that long-term care environment for more than a brief period, he could lose his government benefits, his place in the day treatment program and his housing. Once he is released from the state hospital, he may or may not receive the help he needs to begin rebuilding his life. A scuffle with local police may land him in the county jail or back in the state hospital. Or if he is released to no one and no where in particular, he may soon find himself on the streets.

DEINSTITUTIONALIZATION AND THE COMMUNITY MENTAL HEALTH CENTER: THE TOUGH TASK OF DELIVERING A BETTER FUTURE

The promise of the deinstitutionalization movement of the 1960s and the 1970s was a better life for persons with mental illness. The new community mental health centers (CMHCs) were viewed as a central element in this better life. Yet many unforseen problems have plagued both the dream of deinstitutionalization and the effectiveness of the CMHCs during the last two decades.

While many laudable examples exist of community mental health systems that have come to offer a genuine and comprehensive alternative to institutionalization, confusion was far too often the result. Uncoordinated planning efforts between federal, state and local governments contributed to this confusion. Such efforts resulted in deinstitutionalization policies and practices that often did not fully account for existing private, quasi-public and public mental health service providers, or how they could work together to ensure a continuum of community-based services linked to the CMHC.

The federal Community Mental Health and Mental Retardation Centers Construction Act of 1963, which threw federal support and money behind the new CMHC approach, officially outlined many of the ideals of deinstitutionalization. State deinstitutionalization programs were soon to follow. And the stage was set for several key coordination problems.

Uncoordinated Care Between the Hospital and the Community. The CMHC was to be the hallmark of a "bold new approach" in mental health care, substituting "comprehensive community care for custodial institutional care" (1, p. 3380). As such, the CMHC was basically a new treatment entity, designed to supplant the old state hospital.

- Its scope would be geographically rather than clinically determined, covering a catchment area of 200,000 to 250,000 people.

- It was envisioned not only as a place, but as its own self-contained, comprehensive system of care that would eventually assume total responsibility for the mental health needs of the citizens in its catchment area (3, p. 762).

As the network of CMHCs would eventually replace the state hospital system, efforts to integrate the two systems became of secondary importance to the task of getting the new treatment centers established and relocating state hospital residents. The hospitals were not assigned any definite place in the interlocking matrix of community-care systems. Moreover, as the ideal CMHC would theoretically assume the task of aftercare planning, many state hospitals discontinued their aftercare planning programs (4, p. 497). Thus the stage was set for frequently uncoordinated care between the hospital and the community.

Treatment Gaps and the Need for a Continuum of Care. The CMHC approach was largely based on a public health model of prevention. The successful development of anti-psychotic medications, combined with a new treatment philosophy that stressed integration rather than isolation of persons with mental illness had infused the mental health establishment with a new optimism about the future of mental health care. The hope was that CMHCs could eventually be used to limit the incidence and severity of mental illness.

Several widely-held misconceptions about the nature of mental illness had contributed to this optimism about the effectiveness of the CMHCs.

- Many still believed that "all mental disorders, including schizophrenia and manic depressive psychosis. . .were caused by aberrant early childhood experiences" (5, 11), and thus were largely treatable by traditional psychotherapy that helped patients come to understand themselves.

- Social conditions, such as racism and poverty, were often cited as causes of mental illness, so "treating" mental illness would involve eradicating these unhealthy social conditions (5, p.11).

- The state hospitals themselves were seen as "[contributing] largely to the chronicity of the patients' disturbance and [making] them increasingly dependent on the State Hospital for survival" (1, p. 3377), so merely transferring the patients to a more hospitable environment might improve their condition.

While the research of the last decade has largely indicated that serious mental illnesses are brain diseases, like Multiple Sclerosis and Alzheimer's disease (5, p. 12), and has done much to dispel the notion of "curing" persons with serious mental illness, such a general understanding did not exist at the beginning of the deinstitutionalization movement. The CMHCs were going to be the country's "main line of defense in reducing the need of many persons with major mental illness for prolonged or repeated hospitalization" (1, p. 3379).

As a result of the belief that, through community-based care, "the development of more serious mental breakdowns [could] be prevented" (1, p. 3379), many CMHCs simply failed to develop plans for the difficult-to-treat client. The CMHC failure to recognize the needs of the difficult-to-treat populations was evident in the treatment settings they established. Community treatment generally involved loosely constructed programs divided among various service

providers. Such programs are often inaccessible to individuals with serious mental illness who have trouble handling stress and negotiating service bureaucracies (6, p. 15-16).

Many seriously mentally hospital patients who still were and probably would always be in need of the diverse services traditionally supplied by the state hospital, were thus released to communities with no functional alternatives to those services. Treatment gaps began to appear in the service continuums that the local mental health programs were supposed to provide. The tenacious problems of the more chronic clients, which proved unresponsive to mere changes in treatment setting, widened these gaps.

For a variety of reasons, many states and communities were slow to recognize--and to coordinate the services to meet--the long-term care needs of those persons with major mental illness whose needs could not be met by the traditional CMHC.

- State mental health planners, who had to make the transition from planning for the "intact communities" of the state hospitals to planning for a network of widely scattered community-based services, were already facing a greatly complicated task (1, p. 3401).

- Many communities had their hands full trying to coordinate the services their CMHCs could provide. Even those persons with mental illness who were perfectly capable of functioning in the community required a good deal more than mere mental health services. They needed an appropriate place to live, as well as support and general social services. These included case management, socialization programs and vocational rehabilitation and employment assistance. Unforseen turf battles among service providers and scarce resources plagued efforts to provide this care.

- It is unclear who had ultimate responsibility for the welfare of clients whose needs could not be met by the community mental health systems. Some argue that many CMHCs shied away from responsibility for persons with serious mental illness because the needs of that group were often so great "that properly providing them with treatment and care would make it extremely difficult for CMHCs to effectively serve other groups or carry out their other important missions" (1, p. 3404). Others believe that "from the beginning...the 'bold new approach' [of the CMHCs] was being used primarily for psychotherapy on patients with interpersonal problems, and that the patients with serious mental disorders were being ignored" (5, p. 13).

What might have led to a reinstitutionalization of the persons with serious mental illness was stopped by another phenomenon. Accompanying the deinstitutionalization movement was a movement to protect the rights of the individuals during involuntary commitment proceedings. States began to legislate maximum commitment periods and to put legal safeguards in place that made involuntary commitment more stringent. Key court cases, such as *Wyatt vs. Stickney* and *Donaldson vs. O'Connor*, mandated minimum levels of care in state hospitals, as well as treatment settings that were "least restrictive" (5, p. 16).

As a result, even those clients who could benefit from inpatient care were forced to remain in the community or become part of the "revolving door" syndrome, cycling back and forth between the hospital and the community. Recent state efforts to liberalize involuntary commitment laws indicate that the debate over patients' rights in this area is still very much alive.

Funding Patterns Complicate Coordination Issues. The various funding strategies and patterns of the deinstitutionalization movement often ended up encouraging uncoordinated, incomplete care of the persons with serious mental illness.

- States were not nearly as willing--or able--to shift resources to the communities as they had been willing to shift patients. Many states found it politically difficult to

close their state hospitals; as a result, the fixed costs of running the hospitals remained high. Many states felt a continuing obligation to the communities in which the large state hospitals had been major employers and revenue sources (3, p. 764) and were reluctant "to confront the politically powerful state employees' unions" (5, p. 18).

- When the money that had been used to support the patients in the state hospitals did not follow them into the communities, the communities had less money to establish the programs that would necessarily be a part of a continuum of care. More persons with serious mental illness began cycling in and out of the state hospitals, thus perpetuating the need for the hospitals and their continued financial support.

- Inflation began to escalate the costs of state hospital care. The number of patients receiving inpatient care decreased, but mental health dollars spent on such care ran an increasingly ragged race with the national economy. In addition, the nature of the hospital populations changed. Those patients that remained in or were readmitted to the state hospitals generally had more serious and chronic problems, requiring more intensive--and expensive--care.

- Federal Medicare and Medicaid programs, as well as many insurance programs, generally did not provide reimbursement for many of the social services needed by individuals with serious mental illness living in the communities (7, p. 390). Thus local governments, unable to support the costs of such social services, began to focus more on providing reimbursable medical services rather than on providing a continuum of care.

- Federal support for the persons with serious psychiatric disabilities living in the communities constituted a powerful inducement for states to "dump" their patients out of the state hospitals, where they were the state's financial responsibility, and into the communities. Following the passage of the federal 1963 CMHC legislation, persons with mental illness became eligible for federal Aid to the Disabled (later incorporated into the Supplemental Security Income Program), Social Security Disability Insurance, select Medicare and Medicaid benefits, and Food Stamps (5, p. 15).

- The goal of the 1963 legislation--to provide "seed money" for the establishment of CMHCs until states, localities and third-party reimbursement programs could pick up the costs--proved to be particularly elusive. Subsequent amendments to the federal legislation extended support to the CMHCs considerably beyond the point originally intended. In 1970, for example, in increasing the federal share of center construction costs, the Congress concluded that "earlier optimism regarding the progressive development of funding resources. . .proved to be too optimistic" (1, p. 3384). Moreover, it became increasingly clear that "localities in the greatest need of community-based mental health services. . . [had] been least able to organize, plan and raise sufficient funds" (1, p. 3384).

Later Problems. In addition to the initial problems that discouraged coordinated care for persons with mental illness in the community, federal funds for social and mental health services have decreased dramatically. The federal Mental Health Systems Act of 1980, for example, which authorized grants for a variety of purposes related to community mental health care, was largely repealed in 1981. Competition for the remaining funds among state and local social service agencies has increased, augmenting existing pressures to protect agency turf and increasing resistance to interagency communication and cooperation.

GENERAL LEGISLATIVE GUIDELINES

While states cannot remedy all the problems wrought by the deinstitutionalization policies of the past, they can do much to ensure a future of coordinated care. Possible areas for legislative action include:

- Requiring or encouraging coordinated planning through interagency agreements and guidelines;
- Restructuring the state's mental health administrative branch in order to facilitate coordination;
- Delegating the specific authority to coordinate mental health services by delineating leading and supporting roles among state agencies and by extending the mandate to include all the agencies involved;
- Authorizing local mental health authorities to develop a more comprehensive system within the existing state system;
- Indentifying priorities related to coordination; and
- Monitoring and directing coordination efforts through the budget and appropriations process by tying state funds to the provision of specific or priority mental health services (8).

States also can act to ensure that coordination mechanisms are in place by working to incorporate the system elements that are basic to many successfully integrated community mental health programs:

- A theoretical basis for the service system;
- A single plan for provision of services;
- A single point of funding allocation;
- A fixed, local government entity with authority for and responsibility to provide services in a given area;
- A designated port of entry and exit into the public mental health system or, at least, into the state hospital system;
- A no-refusal policy between all system elements;
- A flexible policy that can respond to the unique needs of the patients; and
- A patient tracking system that keeps patients from being "lost" (9, p. 108-09).

THE STATES' RESPONSE IN RECENT YEARS

In 1987, about 50 laws were passed by 26 states to coordinate mental health services, provide continuity of care, reduce duplication of services, and target resources to clients most in need. The most comprehensive laws were passed by Minnesota, North Carolina and North Dakota. Minnesota (1987 Minn. Laws, Chap. 403) passed a major piece of legislation to establish the Minnesota Comprehensive Mental Health Act to ensure a unified, accountable, comprehensive service system. North Carolina (1987 N.C. Sess. Laws, Chap. 873) required the development of a comprehensive plan to provide a continuum of care for persons with severe

mental illness. North Dakota (1987 N.D. Sess. Laws, Chap. 572) required the development of a plan for a continuum of services for individuals with serious mental illness.

At least five states addressed coordination of children's services in 1987: California (1987 Cal. Stats. Chaps. 160 and 1361), Illinois (1987 Ill. Laws, P.A. 85-725), Maine (1987 Me. Laws, Chap. 181), New Jersey (1987 N.J. Laws, S.J. Res. 36) and Texas (1987 Tex. Gen. Laws, Chap. 956). California (1987 Cal. Stats. Chap. 617) established two pilot projects to provide a comprehensive and coordinated system of care for older persons and functionally impaired adults.

At least three states required aftercare plans for inpatients or follow-up for patients referred elsewhere in 1987, including Illinois (1987 Ill. Laws, P.A. 85-308), Maryland (1987 Md. Laws, Chap. 576) and New Jersey (1987 N.J. Laws, Chap. 116). Screening mechanisms were instituted by Indiana (1987 Ind. Acts, P.L. 214), New Jersey (1987 N.J. Laws, Chap. 116), Rhode Island (1987 R.I. Pub. Laws, Chap. 66) and Texas (1987 Tex. Gen. Laws, Chap. 956) to better ensure appropriate placement or services for clients.

In 1987, many states realized the need to coordinate services and provide continuity of care of clients with dual diagnosis (those with more than one serious problem). Arizona (1987 Ariz. Sess. Laws, Chap. 88) and Florida (1987 Fla. Laws, Chap. 106) passed legislation focused on individuals who are homeless and mentally ill. New Jersey (1987 N.J. Laws, Chap. 32) and Oklahoma (1987 Okla. Sess. Laws, Chap. 12) turned their attention to clients who were developmentally disabled or mentally retarded and mentally ill; and California (1987 Cal. Stats., Chap. 1261) addressed the treatment needs of clients who are chemically dependent and mentally ill.

At least six states turned to case management in 1987 as a way to improve service coordination for persons with mental illness. California (1987 Cal. Stats., Chap. 1384), Colorado (1987 Colo. Sess. Laws, Chap. 217) and Wisconsin (1987 Wis. Laws, Act 27) added case management services for persons with mental illness to their medical assistance programs in 1987. Arkansas (1987 Ark. Acts, Act 1053) required community mental health centers to use a coordinated case management system. Maine (1987 Me. Laws, Chap. 246) defined case management services, and North Carolina (1987 N.C. Sess. Laws, Chap. 422) enabled counties to develop case management services and a single portal of entry for human services.

In recent years, state lawmakers have attacked the problem of uncoordinated care for persons with mental illness from a variety of angles. A number of states have worked to establish an interlocking matrix of local programs, tied together by a central mental health authority or by some kind of statewide plan for mental health services. The following are examples:

- Florida (Fla. Stats. § 394.65-394.81) established a statewide network of service districts for the treatment of mental illness and substance abuse, overseen by a network of planning districts;

- Georgia (1976 Ga. Laws, p. 1136) provided for the development of a statewide plan for provision of coordinated mental health services by establishing community mental health and mental retardation service areas, overseen by advisory councils;

- Iowa (1981 Iowa Acts, Chap. 78) centralized administrative authority for mental health in the state Division of Mental Health, Mental Retardation and Developmental Disabilities and directed counties to establish county mental health and mental retardation coordinating boards; and

- Washington (1982 Wash. Laws, Chap. 204) defined the roles of the state, the counties and the individual service providers in the state mental health system and delineated responsibilities for continuum of care and coordination.

Similarly, New York (New York Ment. Hyg. Law § 41.19, 41.21, 41.23) and Wisconsin (Wis. Stats. 51.42 and 51.437) both made use of the "unified services" concept, which aims to integrate the various mental health services provided in a given region, in their state's blueprint for mental health services. Wisconsin required each county to develop a unified services plan for its catchment area. New York offered--and five counties accepted--the option of developing such comprehensive plans. Subsequently, New York (1986 New York Laws, Chap. 746) consolidated two separate programs providing aid to counties for persons with serious mental illness into one program to be channeled by the Office of Mental Health through each county. This new law will allow counties to opt for greater responsiblity and control of the provision of community support services.

Some states have attacked the problem of uncoordinated care through the creation of coordinating boards or councils. Nevada (1985 Nev. Stats., Chap. 672) established its state commission on mental health and mental retardation in part to coordinate services on a statewide basis. Nebraska (1986 Neb. Laws, L.B. 675) created the Mental Health Advisory Commission to advise on the provision of the comprehensive and integrated mental health services plans. In addition, Indiana (1986 Ind. Acts, P.L. 21) now requires the Interdepartmental Board for the Coordination of Human Service Programs to plan for a continuum of mental health services, while New York (1986 N.Y. Laws, Chap. 20) established the Mental Health Services Council to advise on the improvement of mental health services.

Similarly, Texas (1983 Tex. Gen. Laws, Chap. 308) established the Texas Health and Human Services Coordinating Council to develop procedures for ensuring coordinated care between the state's human service agencies, including those involved in providing services to persons with mental illness. The work of the Coordinating Council helped prompt passage of a 1985 bill (1985 Tex. Gen. Laws, Chap. 496) mandating the development of a long-range plan for mental health services and the provision of certain minimum services in each service area. Arizona (1986 Ariz. Sess. Laws, Chap. 398) went one step further by creating a new Division of Behavioral Health to coordinate mental health services.

Two states made an effort to coordinate provision of mental health services without creating a separate supervisory board or council. Maine (1986 Me. Laws, Chap. 27) now requires the development of an interagency plan to remedy gaps in mental health service to clients in each of four state agencies. Michigan (1986 Mich. Pub. Acts, Act 149) has instituted new reporting and assessment requirements to better coordinate provision of services. Under the act, each county mental health board must report annually on the extent of the area's mental health needs and the availability of services to meet these needs. The Department of Mental Health then must compile the county information for an annual needs assessment report to the legislature.

Still other states have directed considerable effort towards bridging the gap between the hospital and the community. The following are examples:

- Arizona (1984 Ariz. Laws, Chap. 127), established an Arizona State Hospital Advisory Board to help devise goals for the state hospital and to offer advice on the coordination of services, programs and policies between the state hospital and the community mental health care programs;

- Illinois (1985 Ill. Laws, P.A. 84-918) aimed to secure and maintain adequate financial benefits for those individuals admitted to and released from the state hospital by requiring interagency agreements to that effect;

- Oregon (1981 Ore. Laws, Chap. 750) required agreements between community mental health programs and the state hospitals to ensure a continuum of care for patients admitted to and discharged from the state hospitals;

- Indiana (1986 Ind. Acts, P.L. 28) now regulates the transfer of patients to outpatient status and requires that "service monitors" oversee individuals' treatment plans; and

- Maryland (1982 Md. Laws, Chap. 348), Oklahoma (1986 Okla. Sess. Laws, Chap. 35) and Virginia (1986 Va. Acts, Chap. 309) extended requirements for predischarge treatment plans.

Select states have also targeted certain priority populations or services in their efforts to build an integrated system. At least four states, for example, have passed legislation consolidating administrative authority and responsibility for services to mentally ill children: Connecticut (Conn. Gen. Stats. § 17.410 - 17.447); Delaware (Vol. 64 Del. Laws, Chap. 108 (1983); New Hampshire (1983 N.H. Laws, Chap. 416); and Rhode Island (1979 R.I. Pub. Laws, Chap. 248). Michigan (1984 Mich. Pub. Act, Act 186) took a slightly different approach when it established a single port of entry/single exist system for mental health services for children and standardized treatment procedures throughout the state.

California consolidated its services to the homeless mentally ill by requiring the establishment of at least six social support agencies to coordinate comprehensive mental health and social support services for the homeless mentally ill on a regional basis (1985 Cal. Stats, Chap. 1286).

Moreover, a number of states have paid significant attention to the coordination and development of adequate community-based residential services. For example, Hawaii (1980 Hawaii Sess. Laws, Act. 221; 1985 Hawaii Sess. Laws, Act. 219) provided guidelines for the establishment of a statewide system of residential treatment programs that provide a range of alternatives to institutional care for persons with mental illness. New York (1984 N.Y. Laws, Chap. 298) authorized the commissioner of mental health to establish a continuum of community residential services for the mentally ill, providing up to 100 percent state reimbursement of costs associated with these residential programs.

FUTURE IMPLICATIONS

Federal money to the states for general mental health and social services probably will continue to decrease. States will thus be forced to spend more of their general mental health budgets on supporting the state hospitals, unless they take definitive action to tranfer funds and authority to the local governments already responsible for caring for the vast majority of the nation's individuals with serious mental illness.

Local governments probably will become increasingly unwilling--and unable--to bear the ultimate responsibility for individuals with serious mental illness living in their communities as more federal and state funds are drained from their local programs. Yet local governments must be ultimately responsible for the care of the mentally ill within their domain if the community-based mental health system is ever going to work.

Moreover, states must be realistic about what a future of fiscal austerity promises for a system made up of discrete service agencies, all vying for their own survivial. Turf battles between the agencies involved in the commuinty-based mental health system can only increase as competition for available funds increases. These agencies probably will become increasingly resistant to working together if such cooperation is perceived as a threat to their financial survival as well as to their administrative autonomy.

Yet a future of increasing admissions to state hospitals and decreasing cooperation among mental health providers is not inevitable. In the 1970s, for example, Wisconsin effectively recast its mental health system from one of institutionally based care to one of locally based care. This redirection effort involved the development of unified services plans for each catchment area, of community support programs and of alternatives to inpatient hospitalization for persons in crisis. State legislation shifted treatment authority and responsibility to local mental health boards.

Moreoever, every state has at least some success stories of community-based programs that genuinely offer the individuals of mental illness a better, more productive life. State legislatures can help build a better future for this population by learning the lessons of success within their own borders, as well as from other states.

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13. Remarks of Richard C. Surles, Ph.D., Administrator, Philadelphia County Office of Mental Health and Mental Retardation. At Pennsylvania Technical Assistance Program, October 1985.

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